

LymeDisease.org's newest published study shows the importance of paying attention to individual treatment response instead of just averages

"Super responders" are key to personalized Lyme disease treatment



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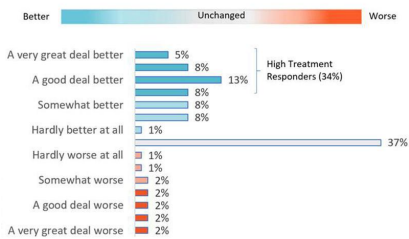
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LOS ANGELES, Oct. 23, 2018 /PRNewswire/ -- The medical community is at odds on how best to treat Lyme disease in patients who do not respond well to short-term antibiotics. Those patients may then try a variety of other treatments – which may work better for some people than others.

A recently published study shows the importance of identifying "super responders," people who respond particularly well to treatment. Finding out who responds well to which treatment – and then learning more about those people – is an important step towards developing personalized medicine for Lyme disease.

34% Are High Treatment Responders

In general, I would say that with antibiotic therapy my Lyme disease symptoms are. . .



More than half (52%) reported at least some improvement, with more than a third (34%) saying that they improved “moderately” to “a very great deal”. Slightly more than a third (37%) had no treatment response. Only 12% reported that their symptoms were worse after treatment.

The recent study "Removing the Mask of Average Treatment Effects in Chronic Lyme Disease Research Using Big Data and Subgroup Analysis" was published in Healthcare by Lorraine Johnson, principal investigator of MyLymeData (a project of LymeDisease.org), Dr. Jennifer Mankoff, Richard E. Ladner Professor in the Paul G. Allen School of Computer Science and Engineering University of Washington, and biostatistician Mira Shapiro.

The study reviewed treatment responses of nearly 4,000 patients with late or chronic Lyme disease. Looking only at "average" figures, it appears there was little response to treatment, according to Lorraine Johnson of LymeDisease.org.

"However, breaking them into sub-groups presents an entirely different picture," Johnson said.

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"There is no average Lyme disease patient," emphasized Johnson. "We need to move away from looking at treatment response averages, and instead, figure out who recovers from Lyme disease and why, in order to provide individualized care."

The Centers for Disease Control and Prevention (CDC) estimates that 300,000 new cases of Lyme disease occur annually. While many patients who are diagnosed and treated early are restored to health, a reported 10%-35% do not recover. Furthermore, many patients are not diagnosed until later in the disease, when Lyme is much harder to treat.

"First, we need to determine what factors drive treatment response in certain groups of patients. Then we can apply that knowledge to other patients to increase treatment success rates," Mankoff explained.

In the past, studies about chronic Lyme disease treatment have used very small samples (the largest enrolled just 129) and highly restrictive enrollment criteria. The three studies funded by the National Institutes of Health were too small to look at individual variations in how patients responded to treatment. Instead, they lumped the patients together, looked at average treatment response, and produced conflicting results. According to Shapiro, "using averages like this leaves out the most important information—the individual treatment variation."

The study is available via open access (without charge) at <https://www.mdpi.com/2227-9032/6/4/124>.

A video abstract is available at https://www.youtube.com/watch?v=_TwYXI08ZTg.

Author interviews are available upon request.

About LymeDisease.org

LymeDisease.org's mission is to empower patients through science-based advocacy by providing them with the educational, communications, advocacy, and research tools essential to improve our understanding of Lyme disease and develop effective diagnostic tests and treatments.

About MyLymeData

MyLymeData is a patient registry and research platform that was developed and launched by LymeDisease.org in 2015. It uses big data research tools that allow patients to pool their data quickly and privately to determine which treatments work best. Over 11,000 patients have enrolled in the registry, which is now in the top 5% of patient-driven registries in the nation. The registry remains open for enrollment.

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